

Comments of Dave Meador  
Vice Chairman, DTE Energy  
Co-Founder, Autism Alliance of Michigan  
Michigan House of Representatives  
Education Committee  
April 21, 2016

Thank you Madam Chair and Members of the House Education Committee.

Good morning. My name is Dave Meador. I wear several hats. I am the parent of a 20-year old daughter on the spectrum. I am also the co-founder of the Autism Alliance of Michigan and one of our roles is education and advocacy regarding the issues facing families with autism. My day job, amongst others, is as the Vice Chairman at DTE Energy.

My wife, Peggy, could not be here but she is very passionate about the issues you are reviewing.

Let me start with a macro perspective:

Many schools are regularly using restraint and seclusion to attempt to control student behavior. Although the federal government has talked about taking action after hearing about scream rooms, children being duck-taped to desks and other horrendous stories including children dying while restrained, we can't wait. It is time for Michigan to take action.

While we don't have good data in Michigan on restraint and seclusion, in states that collect data you would find that about 40% of the restraint and 50% of the seclusion events involve students on the autism spectrum.

In state's like Connecticut, who have statute indicating that restraint should be only used in "emergencies," the numbers are not much better. More disheartening is that in some states that have data - about half of the incidents involve children in grade 5 and below, including kindergarten and pre-K.

It's unfortunate that we need state statute. Peggy and I believe that if the federal education law, IDEA, was followed many of the behavioral issues would be avoided and we would not be talking about tying children up.

IDEA speaks to the requirement that teachers be highly trained in evidenced-based teaching methods, that the child's IEP include the results of a functional behavior analysis and a responding behavior plan.

If the child has speech, language and behavior issues the IEP should address techniques like front loading, transition management, visual management and other techniques to avoid behavior issues and de-escalation techniques when they occur.

Unfortunately, research done by MSU shows that this is not the case in many Michigan schools. IEPs are often poorly written, don't include behavior and academic plans, and are set in a context of low expectations. This is why the Governor called for the Special Education Task Force.

We believe strongly that a team trained in behavior analysis can develop and activate plans that will avoid almost all escalated behavior situations.

In our family's case, we used an approach – which was embedded in the IEP – behavior escalation framework with a scale of one to four, with four being the worst behavior. We replaced the conversation of what we would do at level four, or explosive behavior, with the technique of never going to a level two by using de-escalation interventions.

My daughter was restrained in middle school several times even though we had a functional behavior analysis and a behavior plan. Restraint wasn't ever mentioned or in the plan.

It is one of our darker moments in her and our entire lives. I remember thinking at the time, "how could it be that the very people that we entrust our children to – would physically assault her, traumatized her, humiliate her and break her trust in adults, especially men."

However, at the time, the teachers felt strongly this was the way to handle things and to teach her a lesson. The scary thing is some, not all – teachers still feel this way today. On April 17th, MLive quoted a Michigan teacher saying restraint is ". . .valuable for teaching self control. And that we just need to let teachers do their jobs." That is a pretty scary statement. We don't even treat dogs like that.

So here is the story about my daughter:

In middle school we started to see behavior issues in school only, not at home. We used a certified behavior therapist, but at the time our school would not consider using any of the techniques.

We came to understand they said the right words about behavior and applied behavior techniques, but they not only didn't understand or have the skills, they often did the opposite. We started to see worse behavior at school and none at home. We asked the school to let us bring in a certified ABA therapist and we would pay for it and they said no.

We later learned that one of the things that was prompting some of the behavior was the school's special education aides teasing our daughter. They would also routinely reprimand her and scold her. These are not evidenced-based methods on how to deal with behavior. Actually, it was harassment.

This was in 2008 and 2009 – there were several restraint events. We will never know exactly what happened, how long the restraint was and how intense it was. Getting information even with a lawyer by our side was difficult. The school couldn't explain what prompted the behavior and why. They couldn't explain why they didn't call my wife who was five minutes away.

The impact on our daughter was immediate and devastating. Can you imagine the impact on a child by the institution and adults that you have been taught to trust? To be physically assaulted by the staff was traumatizing, humiliating and caused long-term harm to our daughter, similar to PTSD. This is one of the reasons my daughter has a service dog today.

Our daughter described these events at the time in tears, trembling and shaking and said it was like a lion coming to kill her. She told us she couldn't breathe during the assault. She had frequent nightmares and constantly talked about predators coming to get her and hurt or kill her.

I asked my daughter about the events from 8 years ago this week, she said "it was like a pack of wolves coming to hunt her, she couldn't breathe, they wanted to kill her, it was like a large anaconda snake trying to kill her and stop her breathing and then put her in a cage like a dog." That is her memory of middle school.

My wife and I were traumatized. We let our daughter down. The fact that she had autism was not her fault. The fact the school brutalized her was our fault.

With the help of therapy, our daughter eventually grew past this, but she lost a couple years in education.

The school was never able to answer many questions. It wasn't clear why they violated their own non-violent CPI training and their own written procedures. We believe at least one restraint was for over an hour, violating the MDE rule of 20 minutes.

In one case, our daughter was in a seclusion room by herself and doing no harm to herself or anything. The school could have left her there and called her mom or me. What we learned was the two male aides, by the way – the two that would tease and taunt her, – decided for an unknown reason to enter the room and restrain her. We were later told that this is part of the behavior plan to "teach her a lesson."

Under threat of a lawsuit, that I am certain we could have made a class action suit due to the pattern of attacks on children, the school allowed a BCBA to come in and do what they should have done – a functional behavior analysis, develop a behavior plan and taught the teachers and aides applied behavior techniques. And guess what – most of the behavioral issues subsided and there was not a need to even come close to restraining her.

We couldn't trust this school anymore and we pleaded with the Superintendent to set up a high school autism program. They hired a gifted teacher who worked closely with the behavior therapist and used evidenced-based teaching techniques. And to everyone's surprise our daughter went from a self-contained classroom to 100% mainstreamed, 100% on task, learning and taking tests in classes like Japanese and gave up her aide to demonstrate her independence.

With the right approach, everything clicked in and she could be her best.

My wife and I, and the Board of the Autism Alliance, support House Bills 5409 to 5418 and ask that the House Education Committee support passage here and then on to the full House.

The legislation is well researched and well written. I have a couple suggestions:

House Bill 5409 says that it "encourages" the use of proactive, effective, evidenced-based strategies and best practices to eliminate the use of seclusion and restraint, the federal laws require this today and it is often ignored. I would ask that you eliminate the word "encourage." Schools should comply with IDEA and stop calling it an unfunded mandate. The words should be written "schools shall" with some penalty for non-compliance.

House Bill 5412 refers to emergency seclusion and restraint. Please note any emergency restraint and seclusion, which should be very rare, should be done with cameras filming the entire situation. Remember 40% of students with autism don't talk and can't explain who did something to them or what they did. Parents shouldn't have to take pictures of their children before and after school to determine if they have been abused today at school.

House Bill 5413 refers to reporting to parents "as soon as possible." Why not immediately? In the section of the bill that is an after action review, part of the review should include an analysis of why the de-escalation techniques didn't work and what should be done differently next time.

House Bill 5415 – I would like to see the requirement to have the data detailed by diagnosis, age, race and gender. And would like to have special reporting for any teacher or aide that has performed multiple restraints or seclusions.

House Bill 5416 – you might consider First Responder training, and coordination with the local police and fire personnel that Autism Alliance of Michigan has trained. I am aware of one situation in Troy with another child with behavior issues that Troy police were called and not told by the way the student has autism. The Troy police assumed they had some other behavioral issue and handcuffed the student and dragged him out of school. You might consider in those rare emergencies that police are called, that the police be notified that it is a special education student or a student with autism.

In summary, my wife and I encourage you to pass this legislation.

Thank you.